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Sanders, Phoebe; Wadey, Ross; Day, Melissa; et al.

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## Abstract

The objectives of this research were to extend previous research by exploring the psychosocial experiences of patients over the first year after major lower limb amputation (MLLA) and identify implications for rehabilitation practice. This research took place at a UK-based, National Health Service-operated prosthetic rehabilitation centre. Thirty patients were recruited who had experienced MLLA within the last year and were undertaking prosthetic rehabilitation. Data were collected through semi-structured narrative interviews, observation, and a reflexive journal, and analysed using dialogical narrative analysis. The concept of well-being was used to map patients' recovery trajectories, and five narrative typologies were identified: *accelerated decline*, *adaptation*, *illusory cure*, *muddling along*, and *projection*. This article advances knowledge by opening up new possibilities for anticipating patients' future needs through the stories they are telling in the present and provides the basis for additional resources supporting psychosocial recovery.

## NARRATIVES OF RECOVERY AFTER MLLA

### Narratives of recovery over the first year after major lower limb loss

Amputation is the surgical removal of a part of the body, such as an arm or a leg (NHS, 2016). This article focuses on major lower limb amputation (MLLA), which involves removal of one or both lower limbs at any point above the ankle. The primary cause of MLLA in the United Kingdom (UK) is peripheral arterial disease (PAD; a blood circulation disorder that causes blood vessels to block, narrow, or spasm) resulting from type II diabetes. The most recent Public Health England data put the diabetes-related amputation rate at 20 per day (Diabetes UK, 2018a), and this is likely to increase, with 12.3 million people at increased risk of type II diabetes (Diabetes UK, 2018b). The high prevalence of MLLA in the UK is placing significant demands upon an already stretched health service. In 2010, the estimated annual cost of lower limb amputation was between £50 and £75 million, representing approximately 0.5 per cent of the total National Health Service (NHS) budget (Moxey et al., 2010). More recently, it was reported that amputations related to diabetes alone cost the NHS more than £120 million each year (Brimelow, 2012).

Such figures show the importance of research and interventions targeting the prevention of diabetes and amputation, such as Diabetes UK's 'Putting Feet First' campaign. However, changing health-related behaviors is very difficult (e.g., Kelly & Barker, 2016), therefore, the number of individuals undergoing diabetes-related amputations is likely to decrease slowly. Also, diabetes is not the only cause of limb loss. While campaigns focused on prevention may help to lower the risk, those who do experience MLLA still require effective support. Therefore, the emphasis placed on prevention of diabetes-related amputation must not overshadow the importance of providing support for those who do undergo MLLA, which may affect patients' physical functionality, psychological, and social experiences (e.g., Horgan & MacLachlan, 2004).

The exploration of psychological and social factors in the development and course of illness or disability has been termed the ‘psychosocial approach’, which has been formalized as a distinct discipline in healthcare domains such as oncology (e.g., Mehnert & Koch, 2005). The psychosocial responses to amputation have received significant research attention in recent years as it is increasingly recognized that MLLA can result in radical and existential upheaval (Norlyk, Martinsen, & Kjaer-Petersen, 2013), leading to a long-term and complex adjustment process (Gallagher & MacLachlan, 2001). A wide spectrum of psychosocial responses may occur after MLLA, possibly due to the diversity of circumstances that cause and accompany amputation (Rybarczyk, Nicholas, & Nyenhuis, 1997). An individual’s psychosocial responses to MLLA have implications not only at psychological, emotional, and social levels, but also at a physical level. Depression and anxiety, for example, have been associated with poorer diabetes control, adherence to medication, and self-care behaviors (Pedras, Carvalho, & Pereira, 2018). The first year following MLLA may be a particularly challenging period, as individuals are faced with adapting to numerous changes including reduced mobility and independence, an altered body image and sense of self, and facing the possibility that they may be seen by others as ‘disabled’ (Horgan & MacLachlan, 2004). However, a lack of longitudinal studies with populations who have experienced MLLA (Grech & Debono, 2014; Sinha & van den Heuvel, 2011; Zidarov, Swaine, & Gauthier-Gagnon, 2009) has precluded an in-depth understanding of recovery trajectories in this population.

Given the diverse psychosocial responses that may occur following MLLA, this research utilises the concept of well-being to explore patients’ holistic psychosocial recovery trajectories. Two distinct constructs of well-being are considered: subjective well-being (SWB) and psychological well-being (PWB). SWB is concerned with people’s happiness with their lives and the experience of positive and negative affect. It comprises global evaluations of affect and quality of life (Keyes, Shmotkin, & Ryff, 2002), providing a measure of people’s

responses to their subjectively defined worlds (Campbell, Converse, & Rodgers, 1976). As such, it features in many social and health disciplines interested in quality of life (Raphael, Renwick, Brown, & Rootman, 1996). PWB captures the meaningfulness of those lives through exploring “perceived thriving *via-à-vis* the existential challenges of life” (Keyes et al., 2002, p. 1007). Ryff (1989) explored the points of convergence in prior theories of PWB and proposed that it comprises six core dimensions. The first dimension is self-acceptance or holding positive attitudes towards oneself. The second is positive relations with others, defined as warm, trusting interpersonal connections. The third dimension is autonomy, including qualities such as self-determination, independence, and internal behavioral regulation. The fourth is environmental mastery, or the ability to choose or create environments suitable to one’s own needs. The penultimate dimension is purpose in life, consisting of goals, intentions, and a sense of direction and meaning. Finally, personal growth includes continued development of one’s potential in addition to achieving the preceding five characteristics.

The decision to utilise SWB and PWB as a means of plotting patients’ experiences was made during the analysis process, as it became apparent that these were the dimensions along which patients organically mapped their experiences. These distinct constructs provide a means of understanding the impact of MLLA on patients’ happiness and on their perceived psychological functioning, and consequently for improving the likelihood of positive psychosocial outcomes. As such, they provide a broad and inclusive gauge of each patient’s perception of his or her recovery at different points in time. Corbin (2003) suggested that our bodies speak to us through sensations that are anchored in meaning; when we are unwell, the sensations that we feel may no longer be meaningful. In line with Corbin’s work, recovery is conceptualised in this research as a process of returning learning to trust the body again and returning to a healthy identity. This research is also framed by the stated aim of NHS rehabilitation following MLLA: “to maximise the mobility, independence, and quality of life

of the individual, working in collaboration with the patient as equal partners” (RDCRG, n.d., p. 3). That said, we also remained critical of the “returning to normal” discourse in rehabilitation settings, which can be especially problematic for elderly or seriously ill patients, whose bodily disruption can directly challenge the rehabilitation discourse of returning physical functioning to individuals in a way to reminiscent of their pre-impairment ways of life (cf. Warren & Manderson, 2008).

This research was also informed by Frank’s (2013) three characteristic narratives of serious illness and medicine which act as templates onto which individuals map their personal stories of these phenomena: restitution, chaos, and quest. The dominant narrative of serious illness is one of restitution, with the structure of ‘yesterday I was healthy, today I’m sick, tomorrow I’ll be healthy again’ (p. 77). This is a narrative originating not only from the natural desire to get well, but also from the stories told within medical institutions and the modernist expectation that there is a remedy for every ailment (Frank, 2013). Within the context of limb loss, however, the restitution narrative is problematic; there is no ‘cure’. Where misalignment occurs between an individual’s narrative and his or her real-life experience, narrative wreckage (Frank, 2013) may ensue, threatening the patient’s sense of self, identity, psychological health, and personal development (McAdams, 1993; McLeod, 1997). The chaos narrative, in contrast, imagines life never getting better. This is an anxiety-provoking anti-narrative without sequence that cannot be told, only lived. Adopting this narrative may have a negative impact upon an individual’s engagement with rehabilitation efforts, thus perpetuating the belief that life will never improve. The quest narrative offers the ill their most distinctive voice, telling of the search for other ways of being and of being unwell (Sparkes, 2004). Through this narrative, the patient comes to understand illness as a challenge and a journey, through which meaning will emerge. However, this narrative may also confer certain challenges, for example, deprecating those who struggle to rise after amputation. Therefore, embracing any one of these

narrative types may be accompanied by certain challenges and limitations. In light of such previous work, the objectives of this research were to use a narrative approach to explore the psychosocial experiences of patients over the first year after MLLA and identify implications for rehabilitation practice.

### **Method**

#### **Context of the Research**

This research took place at a UK-based amputee rehabilitation centre operated by the NHS. The rehabilitation centre is located in a community hospital but operates as a relatively self-contained unit comprising a medical clinic, rehabilitation gym, prosthetic workshop and consultation rooms. Patients attending the centre have undergone MLLA due to a variety of causes including vascular conditions, trauma, infection, disease, or congenital defects, and are required to be broadly self-sufficient in acts of daily living (ADL). Patients usually attend the rehabilitation centre full-time for several weeks post-surgery, either on an inpatient or outpatient basis, to learn to use a prosthetic limb. After discharge from the initial rehabilitation phase, patients will continue to attend the centre periodically throughout their lifetimes for ongoing health checks and prosthetic reviews.

#### **Research Paradigm and Methodology**

This research was underpinned by interpretivism; that is, ontological relativism (i.e., reality is multiple, created, and mind-dependent) and epistemological constructivism (i.e., knowledge is constructed and subjective). Narrative inquiry was adopted as the underpinning methodology as it conferred certain advantages to the research. First, stories may be a means by which people make sense of their lives after serious illness or injury (Frank, 2013). Using a narrative approach provided a means of understanding how patients constructed their experiences of the rehabilitation journey by providing a framework for understanding and linking the stories patients told throughout the recovery process. Second, narratives are social



and individuals will draw on the narrative resources that culture, local worlds and relationships make available (Smith & Sparkes, 2009). Listening to patient's stories of rehabilitation may therefore also allow for insights into the cultural narratives operating in the rehabilitation centre, amongst patients' friends and family, and in the media.

### **Sampling and Participants**

Ethical approval was sought from and granted by the University Research Ethics Committee, the NHS Research Ethics Committees, and the Health Research Authority. A maximum-variation, criterion-based purposive sampling strategy (Sparkes & Smith, 2014) was used in an attempt to represent the views of diverse patient groups in the dataset. The sample comprised 30 individuals (20 males and 10 females) aged 22 to 99 years, 17 of whom attended the centre as inpatients and 13 as outpatients. Participants differed with respect to MLLA aetiology (vascular conditions = 18, trauma = 8, infection = 2, other = 2) and level (transtibial = 21, transfemoral, 2, through-knee = 1, hemipelvectomy = 1). All participants were required to: (a) be aged 18 years or over, (b) not be suffering from cognitive impairment, and (c) to have undergone MLLA and participated in prosthetic rehabilitation at the centre in the last year. Individuals who had undergone revision surgery after earlier MLLA were also invited to participate, provided that they were participating in prosthetic rehabilitation. Each participant gave written informed consent prior to participation, which was gained through verbal briefings and written information sheets. Although informed written consent had been sought at the outset, it was not taken for granted that patients would also want to be participants every day. Therefore, there were no criteria for each participant's commitment to the study; he or she could decide to participate in certain elements (e.g., an interview), but not others (e.g. observation), and enter, withdraw from, or re-enter the study at any time. In order to protect participant confidentiality and anonymity, all identifiable information has been removed. These safeguards were also implemented during the external reflections process (see the

‘Research Quality and Rigor’ subsection), in which aggregated patient experiences (as opposed to individual and identifiable patient stories) were presented in the form of narrative typologies. In an attempt to avoid deductive disclosure (Kaiser, 2009), detailed information about participant characteristics has not been included.

### **Data Collection**

Data collection spanned a period of 16 months, following a five-month period of integration into the research field (see Sanders, Wadey, Day & Winter, 2019). Each participant was involved in the research for up to 12 months, staggered across the 16-month period. Participants were invited to take part in up to four semi-structured narrative interviews at a time and location of their choice. Twenty-four took part in at least one formal interview (total = 47, average = 1.74). Interviews lasted between 27 and 163 minutes (average = 68.4 minutes). The first interview took place while hospital-based rehabilitation was ongoing ( $n = 17$ ), followed by additional interviews at approximately six weeks ( $n = 10$ ), six months ( $n = 11$ ), and 12 months post-discharge ( $n = 9$ ). Dropouts occurred throughout the 12-month period for a variety of reasons including failure to return for review appointments, ill health, and loss of life. The remaining six participants either opted to take part only in informal interviews and observation.

Formal interviews took place both within the centre and in other locations of the participants’ choosing (e.g., a café), in which instance the first author, Phoebe, followed the NHS lone working policy. Topics envisaged for the formal interviews included: the patients’ lives prior to MLLA, their experiences during the period between the amputation and the date of the interview, any challenges they had faced, how they responded to these challenges, support they had received, and what support they would have liked to receive. The primary goal of these interviews was to allow the participants to speak of their experiences in their own way and through their own lens, and no two questions were exactly alike. Phoebe explained to

participants that, while she had some ideas of areas that might be explored, the most important topics to cover would be whatever felt important to the participant in that moment. Patients were also able to bring to the interview any items that would help them to tell their stories (e.g., diaries or photographs), which acted as a prompt to elaborate upon the stories they told, fill in any gaps, and explore areas of interest. It was acknowledged that the interviews may include discussion of challenges that patients face following loss of a limb, which some participants may find sensitive or upsetting. Should a participant find a certain topic distressing, they were given the option of moving on to another subject or terminating the interview. The participants were also in control of the scope of the discussion, so were able to manage the exploration of potentially upsetting topics. It was necessary to include questions about these challenges as this issue was integral to the research, and participants were reminded of the availability of clinical psychology support at the centre.

Observation was conducted to supplement, extend, and provide context for the data collected in the interviews (Sparkes & Smith 2014). Phoebe observed in various locations at the centre for up to six hours a day, two days per week, throughout the 16-month immersion in the field. Initially, her focus was primarily drawn to the processes of prosthetic rehabilitation and the daily rhythms of the centre. As the research progressed, this focus shifted towards the various interactions and interpersonal dynamics at play within the centre. It was acknowledged during the ethical approval and consent processes that patients could be observed whilst experiencing physical challenges or psychological distress. To mitigate this risk, participants were required to give verbal consent prior to each period of observation and could also terminate the session at any time. This observation process and its ethical considerations were explored in depth in Sanders et al. (2019). Observations pertaining to consenting participants were recorded as soon as possible using detailed fieldnotes. These notes included what had been seen, heard, and smelled, alongside Phoebe's initial thoughts and impressions. The final

body of fieldnotes totalled more than 40,000 words. Finally, Phoebe detailed her thoughts, feelings, expectations, biases and experiences in a reflexive journal. This practice was maintained throughout the data collection and analysis process, and the final product totalled more than 35,000 words.

Consistent with the recommendations of Wray, Markovic, and Manderson (2007), data collection was ended at the point of researcher saturation. Given the interpretive nature of the research, researcher saturation was considered to be more appropriate than data saturation, since, “to the extent that each life is unique, no data are ever truly saturated: There are always new things to explore” (Wray et al., 2007, p. 1400). Phoebe identified her point of saturation by writing regularly in her reflexive journal and discussing her experiences with her co-authors, who enabled her to debrief and “blend the emotional insider experience back to a cognitive outsider role” (Connolly & Reilly, 2007, p.534).

### **Data Analysis**

Patients’ recovery trajectories were analyzed using dialogical narrative analysis (DNA), which explores what is said in a story, the narrative resources used in its structure, what the story does, and why one chooses a particular story to represent one’s life (Caddick, 2016). Analysis was carried out by Phoebe in regular discussion with a supervisory team. Three supervisors provided a range of expertise in sport and exercise psychology and qualitative methodologies, while one led the hospital’s amputee therapy team (see Sanders et al., 2019). The supervisory team acted as critical friends “encouraging reflection, critique, and exploration of possible insights, interpretations, and explanations arising from the data” (Douglas & Carless, 2009, p.218). DNA was an iterative process that began alongside data collection and continued throughout the writing up phase. The first step was verbatim transcription of the interviews, followed by immersion in the data by reading and re-reading the transcripts and fieldnotes. Consistent with Smith (2013), each patient’s stories were translated into a single

image charting the trajectory of SWB and PWB over time, before and after MLLA. These maps and the stories they represented were discussed between the authors in relation to dialogical questions (Frank, 2012) such as: What narrative resources shape the way the story is told? Who tells which stories to whom? What does this story do for and on the person? To address these questions, Phoebe explored the links, consistencies, and divergences between the stories told by different patients, and the impact these stories had on the teller's recovery trajectory. Distinct typologies were identified that brought together patients whose SWB and PWB followed similar trajectories across time, and who drew on shared narrative resources upon which to hang their individual stories. Finally, writing was used as a form of analysis (Richardson, 2000) to develop, refine, and name the typologies.

### **Research Quality and Rigor**

Five practical strategies were used to support or evidence the credibility, rigor, generalisability, and significance of this research. The first strategy was author self-reflexivity, achieved through Phoebe's use of a written journal to understand how she affected the data collection and analysis process. Phoebe also presented her interpretations of the data to the co-authors, who acted as 'critical friends' by exploring, debating, and reflecting upon possible alternative interpretations of the data (e.g., Sparkes & Smith, 2014; Wadey & Day, 2018; Williams et al., 2018). To increase reflexivity and enhance transparency (Tracy, 2010), the research activities and decision-making processes were documented in an audit trail (Cresswell & Miller, 2000), which was reviewed and interrogated by these critical friends. In the pursuit of credibility, thick description (i.e., detailed participant quotations) is provided in the results section to account for the specificity and circumstantiality of the data, which may otherwise appear divorced from its context (Tracy, 2010). Thick description also provides the reader with evidence to reflect upon and to make connections with their own lives or the lives of others (Wadey & Day, 2018), and may also enhance naturalistic generalisability and transferability

(Smith, 2017). Finally, responses to the findings were invited from key stakeholders to gain a sense of generalisability (Smith, 2017), a strategy referred to by Author Names (2018) as ‘external reflections’. Specifically, the narrative typologies were presented to a group of physiotherapists, prosthetists, and occupational therapists. We decided to engage with a group of staff members rather than patients themselves because we do not yet know the impact hearing these narratives may have upon an individual who has experienced MLLA. In light of extant literature indicating the far-reaching impact that narratives may have upon an individual and his or her health behaviours (e.g., Smith et al., 2015), presenting tentative, unrefined narratives to individuals who may be undergoing a similar experience to that being described presented a risk the authors deemed to be unethical. However, external reflections provided by the staff provided “sensitive but critical insights” (Douglas & Carless, 2009, p. 11). Staff indicated the narrative typologies presented did capture and, importantly, elaborate upon the various recovery trajectories witnessed during their careers in MLLA rehabilitation, and felt they offered a cohesive and coherent framework to make sense of their conversations and experiences with patients.

### **Results and Discussion**

Without attempting to finalise the experience of MLLA, five narrative typologies are presented, each representing the shared recovery trajectory of a particular group of patients over a period of time: *accelerated decline*, *adaptation*, *illusory cure*, *muddling along*, and *projection*. Each typology will be considered in turn and represented in the style of a ‘disrupted realist tale’ (Williams, 2015). To this end, the participants’ quotations and theoretical discussions are punctuated with extracts and reflections from Phoebe’s fieldnotes and reflexive journal. We have attempted to present intact stories where possible, and these are interspersed with theoretical discussion that elucidates the what and how of their telling. Discussion of how these typologies relate to extant research will be interspersed throughout this section, which

will end with consideration of the implications of these findings in healthcare settings. We encourage the reader to reflect upon the typologies presented here and to make connections with their own lives or the lives of others (Wadey & Day, 2018).

### **Accelerated Decline**

The narrative of accelerated decline describes a rapid decrease in SWB after MLLA. Prior to limb loss, these patients were already experiencing a progressive decline in functionality and independence due to aging and/or ill health. Despite this decline, they each retained a degree of independence and autonomy that brought a sense of purpose to their lives (i.e., PWB). After MLLA, the decline accelerated in a way these patients had not anticipated. Losing a limb left them feeling vulnerable and dependent on others, with little autonomy. They looked back to the past with nostalgia, whereas the future was viewed with trepidation and anxiety.

These patients seemed almost to acquiesce to an inevitable downward trajectory of physical deterioration that echoed the dominant aging narrative of decline told in Western cultures (Gullette, 2004). However, the narrative of accelerated decline described by these patients diverged from the traditional narrative of decline as the downward trajectory was no longer considered a normative and natural consequence of aging, but a swift and frightening descent into vulnerability and powerlessness. This experience was described by one participant as she reflected on her experiences in the aftermath of her operation: “I was being hoisted everywhere. That was *horrendous*, I *hated* it. You know, from the bed to the chair, the chair to the commode. Oh, it was awful.” Extant literature suggests that the narrative of decline is oppressive and constraining; it can create a self-fulfilling prophecy regarding the decreasing use of physical and mental abilities over time (Wearing, 1995) and reduce the possibility of self-renewal by trapping people in limiting stories (Freeman, 2000). For those patients embodying a narrative of accelerated decline, the experience of oppression and constraint

## NARRATIVES OF RECOVERY AFTER MLLA

seemed heightened by the sudden and unanticipated drop in autonomy and environmental mastery (i.e., PWB). As a result, they lacked belief in their ability to regain a degree of functionality or independence, or to seek out positive relations with others, contributing to lowered PWB.

Patients' whose stories hung upon this narrative perceived a loss of autonomy (i.e., PWB), in some instances dating back to the point of deciding whether or not to proceed with MLLA. These patients' lives were now governed by medical staff and those they relied on for support at home. This lowered their motivation to engage in rehabilitation as the patients felt powerless to effect positive change. One participant commented: "I know it's bad for this [remaining] leg that I'm not walking around a bit, even. I'm sitting in a wheelchair all the time, which is the worst possible thing for what I've got in this leg. I don't know whether it can get any better with walking." The lowered motivation indicated here may reflect learned helplessness (Seligman, 1975) developed through relinquishing autonomy over their own bodies to medical staff. Upon returning home, these patients struggled to regain the independence lost in the aftermath of MLLA. Each unmet expectation or unachieved goal increased their sense of powerlessness, suggesting these individuals were accommodating the reality of their altered circumstances by shifting their outlook in a negative direction (i.e., I am now powerless). As a result, these patients tended to rely on others to make decisions and effect change for them rather than proactively addressing problems themselves. When others misunderstood, underestimated, or were unable to provide the psychological, social, and practical support these patients desired, their sense of powerlessness increased. This led to feelings isolation and vulnerability, as one participant explained:

The physios told me they will call with regards to re-learning how to use the prosthetic.

The main thing is, in my head, I am worried they don't know how ill I feel all the time and how frail I am. I don't know what to do. Maybe they think I am fitter than I am. I



don't know what to do. . . . It's just this worry that they don't know how ill I am and how vulnerable I am.

These patients fell into a gap in community services: able to care for their own basic needs, and therefore not eligible for government-funded care, but unable to live as they desired (e.g., leaving the house independently, engaging in leisure activities). As a result, even those who lived with a partner or member of family spent a large proportion of their time alone in their houses, which contributed to feelings of depression and anxiety (i.e., lowered SWB). One participant, who lived alone, described the negative impact on her SWB and PWB of being trapped in her house and reliant on other people:

*Participant:* [The occupational therapist] phoned me up one day and I was in floods of tears because I was having a bad day. I hadn't been out at that point; I hadn't been out of the building. But, you know, it's relying on other people. That's never been me. . . .

*Interviewer:* Did you live by yourself before the accident?

*Participant:* Mm-hmm.

*Interviewer:* And were you happy being by yourself beforehand?

*Participant:* Yes.

*Interviewer:* So, what feels different now?

*Participant:* Because I know I can't get out of the building unaided. . . . It feels like I'm caged in, like a caged animal trying to get out, and I can't.

This participant's metaphor of the "caged animal" echoes previous reports that, for patients who have difficulties getting outside, the home may be experienced as a prison in which they feel isolated and confined (Norlyk et al., 2013), lowering perceived environmental mastery (i.e., PWB).

The potentially damaging impact of the narrative of accelerated decline upon patients' SWB and PWB challenges the assumption that older adults are less likely to experience

depressive symptoms than younger people after MLLA (e.g., Rybarczyk et al., 1997; Williamson et al., 1994). While patients embodying the narrative of accelerated decline had accommodated what they considered to be normative decreases in functionality and independence prior to MLLA, they struggled to cope with the sudden and unexpected increase in the rate of decline post-MLLA. This suggests that the age of the patient plays less of a role in their recovery journey post-MLLA than does the narrative resources upon which they draw.

### **Adaptation**

The narrative of adaptation describes an initial sense of loss of a valued past after MLLA, followed by gradual improvement in SWB and PWB. This narrative encourages not triumph over adversity, but adaptation to altered circumstance through assimilation and accommodation. Patients embodying this narrative did encounter challenges in the course of their rehabilitation but were able to respond in a manner that encouraged a shift in focus away from nostalgia for the past towards enjoyment of the present and cautious optimism for the future. This is a progressive narrative, characterized by Gergen and Gergen (1997) as a rudimentary plot structure comprising an upward trajectory of overcoming challenges towards a positive outcome of self-improvement.

The narrative of adaptation differs from the traditional stories of restitution (“yesterday I was able-bodied, today I’m disabled, but tomorrow I’ll be able bodied again”; Smith & Sparkes, 2005, p.1096) and quest (illness is a meaningful journey through which something can be gained) identified by Frank (2013). These patients’ stories were not about seeking meaning (quest), nor about returning to the person they were before (restitution). Rather, they reflected a narrative of adjustment in which valued elements of the patient’s life pre-MLLA were reprised where possible (assimilation), while other elements were relinquished or adjusted in light of new circumstance (accommodation), weaving a path towards a sense of normality rather than self-renewal. It bears similarity to the narrative of progressive redemption,

described by Papathomas, Williams, and Smith (2015) as: “the notion of progressively overcoming difficult scenarios to arrive at some better place further down the line” (p. 7). However, where the narrative of redemption suggests an ability to transform “a bad, affectively negative life scene to a subsequent good, affectively positive life scene” (McAdams, Reynolds, Lewis, Patten, & Bowman, 2001, p. 474), the narrative of adaptation describes a more modest journey towards self-acceptance and a sense of normality rather than self-improvement or betterment. As one participant explained: “I have no grand illusions of walking mountains or running marathons. I just want to get back to that baseline of being able to walk around when I can.”

Patients describing a narrative of adaptation often experienced a decrease in SWB and PWB in the immediate aftermath of MLLA, when they struggled to accept what had happened and the loss of valued future plans. One participant shared with me an entry she wrote in her diary in the days after her operation:

Feeling sad today. Thinking about how I am going to cope and get things done. . . . I feel so useless. My dreams of growing old together with [my husband] have changed. In my mind we were meant to go on holidays and enjoy life, but I know I am just grateful I am here, and I can see my children grow up and grow old with [my husband] and see my family. I just need to stay focused on the future and how lucky I am to be here.

By shifting her focus from the future that she had dreamed of pre-MLLA to a new imagined future, this participant was able to re-discover a sense of meaning and purpose in her life (i.e., improve her PWB). By embodying the story that she was lucky to be alive and should focus on the future rather than the past, she also embraced a belief in the possibility of a shift from a negative to a positive life experience. This belief provided impetus to engage in rehabilitation as a means of regaining a sense of purpose and reprising a valued role and identity in the family.

The same participant explained during her initial rehabilitation: “That’s one of my aims is just to take the kids to school and do the usual ‘mum’ things: cooking and washing up.” The ability to fulfil a role that was part of her identity pre-MLLA facilitated her ability to navigate setbacks and accommodate new constraints while maintaining a relatively optimistic outlook.

These patients’ stories suggested that re-engaging in a valued activity or role is an important means of supporting SWB and PWB through increases in confidence, independence, and self-acceptance. The roles and activities patients described were generally of a functional and modest nature; they spoke of the value and pleasure derived from doing the washing up or driving the car. Norlyk et al. (2013) described a period of ‘existential limbo’ after limb loss, during which participants pushed themselves to re-establish their former lives and to come to terms with their new identity as physically impaired. However, patients embodying this narrative did not seek to recreate their lives pre-MLLA in their entirety. Instead, they built a new life around certain valued activities and roles they were able to reprise at each stage of their recovery. While these participants remained cautiously optimistic with regards to future improvement, they also stressed the importance of living in the moment. One participant described how this shift in focus had improved his life satisfaction and SWB:

My whole life I’ve been thinking, ‘Well, it will be ok when this happens. It will be ok when that happens’, because that was my only way of getting through it. Actually, right now, I’m in a really good place. . . . Ok, I’ve got some stuff that I want to change or worries about surgery or whatever it may be, but to be honest, I’m happy just to go with the flow.

These comments bear similarity to those reported by Grech and Debono (2014), whose participants described learning to live life on a day-by-day basis rather than thinking about the future. For patients embodying this narrative, finding a purpose in the present provided a means

of increasing PWB, as well as bolstering overall life satisfaction (SWB) and optimism for the future.

### **Illusory Cure**

The narrative of illusory cure begins with the experience of very low SWB prior to limb loss. This is followed by a marked increase in both SWB and PWB during the initial rehabilitation phase after MLLA. Patients whose stories hung upon this framework were primarily those for whom MLLA occurred after a prolonged period of great pain, the release from which brought relief and a marked increase in SWB. These patients spoke of the positive affect (SWB) engendered by engaging in daily rehabilitation and developing positive relations with others (PWB) at the centre. Their progress towards environmental mastery (PWB) during this initial rehabilitation phase was generally greater and faster than they had anticipated pre-MLLA. The marked decrease in pain, together with increases in functionality, SWB and PWB that these participants experienced led to a sense of having been ‘cured’, as many of the problems they had experienced prior to MLLA no longer seemed apparent. However, progress faltered once these patients left the secure environment of the rehabilitation gym and returned home, precipitating a progressive and, often, steep decline.

Patients whose stories, over time, described the narrative of illusory cure experienced physical pain and low SWB in the build-up to MLLA. For some, a progressive vascular disorder was causing the affected limb to slowly deteriorate, the experience of which was described by one patient as being like “gradual hell”. Corbin (2003) hypothesized that, in order to perceive a return to health after illness, patients must learn to trust the body again. When viewed against a background of unbearable pain and suffering, it is perhaps not surprising that many patients saw MLLA as a ‘cure’, at least initially. With considered with reference to extant literature, it seems that removal of a limb that was both demanding of attention and disrupting the sense of self (Reeve, 2012) returned to these patients their awareness of and engagement in

the world around them. The challenges of prosthetic rehabilitation initially paled into insignificance in comparison to what these patients had already endured. One participant explained:

When you have something that restricts you, it's like being a prisoner. If you're in solitary confinement for five years and somebody opens a door one day and goes, 'Here's a fresh meadow, go frolic!', how do you think that person's going to feel? I literally have had nothing but pain and suffering for five years, six years, and then somebody's opened the door and gone, 'Here's a field; go frolic! Oh, by the way, here's some wheels as well'.

Previous researchers have identified functional decline post-discharge as the primary concern of healthcare practitioners working with patients with MLLA (van Twillert, Postema, Geertzen, Hemminga, & Lettinga, 2009), but such studies have focused primarily on factors contributing to the decline *after* the patients have left hospital (e.g., difficulties fulfilling family roles, lack of autonomy, loss of motivation; van Twillert, Stuive, Geertzen, Postema, & Lettinga, 2014). This article extends the literature by revealing the kinds of stories patients vulnerable to a post-discharge decline may be experiencing and telling *before* returning home, during the initial weeks after limb loss. During this phase, the patients' stories broadly mirror the restitution narrative (Frank, 2013). For those embodying the illusory cure narrative, the initial pain relief and functional improvement after MLLA, together with the cultural dominance of the restitution narrative, fostered a belief that prosthetic rehabilitation would, in effect, allow them to become able-bodied again.

Embodying the illusory cure narrative raised patients' expectations and influenced the stories they told their friends and families. By telling stories about their 'recovery', the patients surrounded themselves with family, friends, and peers who expected continual progression and a return to the able-bodied person they once were. During interviews conducted during the

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initial rehabilitation period, patients embodying this narrative often brought with them photographs or videos of their injuries and uncomfortable medical procedures they underwent in attempts to save the limb to demonstrate to me how far they had come. This narrative resonates with the concept of false hope outlined by Williams (2015) whereby patients with acquired disability undertook rehabilitation in the unrealistic hope they would make a complete recovery. However, where false hope prompted patients to engage in rehabilitation in an attempt to return to the lives they lived prior to disability, patients embodying the illusory cure seemed to believe that MLLA had already improved their lives. They did not undertake rehabilitation in an attempt to recover, but to build upon the positive changes they had already experienced. Where false hope describes an unrealistic perception of the restorative powers of physical rehabilitation, the illusory cure describes a misplaced belief that well-being has already been restored through MLLA.

When the anticipated progress was interrupted, however, narrative wreckage (Frank, 2013) ensued as the patients' realities no longer supported the stories they were telling; the prosthetic looked and felt less like a cure and the day-to-day struggle of life with MLLA became apparent. The patients' stories ceased to sound like expressions of joy but attempts to make sense of a present that no longer held the promise of a more positive future. One participant explained the negative impact of this experience on his SWB:

The hardest thing is not sitting at home and rotting, you know? It's really difficult. You've got to get motivated and getting motivated can be really hard. There are many mornings, most mornings, I wake up and I'm crying. I'm absolutely crying as I'm tearing myself out of bed, because I actually don't want to get up.

For some, the triggering event was a single incident, such as a fall, which precipitated a loss of confidence and trust in the prosthesis, discouraging further attempts at functional improvement. For most, however, the decline was due to a complex interplay between factors such as

relationship breakdowns, functional challenges, unmanaged depression, and an experience of everyday life as being much harder than anticipated. These challenges seemingly disrupted the patients' goal attainment, and they seemed unable to accommodate their new circumstances in a restitution story. The trajectory of this narrative was such that patients were unlikely to experience the decline in SWB until they were away from the hospital and had less access to professional support. As Frank (2013) noted, "When liberation from the hospital comes, as welcome as it is, one's real trouble begins" (p. 107). This issue was complicated by the patients' apparent reticence to request help, perhaps as they were unwilling to admit they had not, after all, been 'cured'. When I spoke with one participant 12 months after his surgery, he had recently been informed that he needed to have a second operation on his residual limb, he was unhappy in his marriage, and struggling to motivate himself:

I want to do all these things, but I feel almost that I'm not going to be able to do anything until I've had this surgery. It's going to be like, well, am I just going to sit around and do nothing for the next four months? And it's stupid because I was the person that was so motivated to get this done and so motivated after the surgery and so motivated in rehab and so motivated to get home, and when I got home everything was great, apart from the usual getting over having your leg chopped off kind of thing. But it's just plateaued into this bullshit merry-go-round.

Despite openly acknowledging the onset of what he felt to be depression, this participant was unable to articulate what he or anyone else could do to effect positive change. These conversations also demonstrated that it may not be enough to tell patients about the obstacles they might face or how they may address challenges post-MLLA. As another participant summarized: "Rather than just telling people, certainly with people like myself, you need to demonstrate". This research and the narratives that have been identified could make an important contribution in this respect. By creating opportunities and avenues for sharing stories



about life after MLLA, we may be able to facilitate patients' sense-making and construction of their own experiences, encourage positive accommodation, and promote engagement with appropriate sources of support.

### **Muddling Along**

The narrative of muddling along describes a group of patients for whom the affective quality of their life scene was not fundamentally altered by the loss of a limb. These patients told stories about a life of moderate highs and managed lows both before and after MLLA. The unifying thread evident throughout these stories was that some days were good, some days were bad, and these patients made the best of it that they could. The patients who told these stories seemed to separate into two distinct sub-groups: (a) elderly patients who experienced little functional change pre- to post-MLLA, and (b) younger patients who were managing other challenges they felt to be more significant than losing a limb.

The first subgroup comprised primarily elderly patients who were already experiencing functional decline they considered to be normative and in line with their age. These patients had supportive families who helped them to adapt and put structures in place that enabled them to live an enjoyable and relatively independent life despite functional decline. After attending a home visit with one participant and an occupational therapist, I wrote in my fieldnotes:

[The participant] showed me a special contraption that he keeps under the bed, which helps him to pull his socks on. He also has two grabbers, similar to rubbish pickers, to help him pick things up. He had tied a piece of string to the door handle of his bedroom, so that he could grab it when he went past and shut the door from his bed. When [the occupational therapist] said to him that he may find he gets more tired when he comes back home after being an inpatient, he said: "I imagine I will as I get older". Similarly, when [the occupational therapist] mentioned how getting up out of a low chair may be

a lot of effort for him, he said, “Well, you’ve got to make an effort!” and grinned at me.

It’s so easy to forget that he is almost 100 years old!

For this subgroup of patients, the functional limitations brought about by MLLA were seemingly assimilated into a pre-existing and accepted narrative of age-related decline. For the participant described in my fieldnotes, the loss of a limb made his life more challenging, but he was already well-equipped in anticipation of the functional declines he expected as a 99-year-old. As a result, he was able to live independently, socialise with others, and carry out activities of daily living (ADL), all of which contributed to positive PWB. Indeed, much of the equipment provided to patients who have experienced limb loss may be more commonly associated with elderly people: walking sticks, frames, shower seats, and commodes, for example. However, as my fieldnotes illustrate, the participant’s acceptance of functional decline did not deter him from engaging in rehabilitation, but rather motivated him to remain as functionally active as he was able in order to maintain positive PWB and engage in enjoyable activities such as playing bowls and attending church.

For this participant and other members of his subgroup, it seemed to be his advanced age that prevented him from telling stories of progression and increased SWB and PWB. For patients in the second subgroup, who were primarily younger, it was complications arising in other areas of their lives: phantom pain, uncertain housing, other health conditions. One participant was going through a divorce and navigating the complex emotional challenges of moving out of the family home. As I listened to him tell his story during his initial rehabilitation, I (Phoebe) felt concerned that he was in denial about the effect his limb loss had had on him:

*Interviewer:* Do you feel any sense of loss?

*Participant:* No, no, but I’m...I’m aware that I’m...that I have a certain way of dealing with things and that that involves being entirely practical and dealing with the

practicalities of what has to happen and being closed off to the emotional side of it, which is a successful way of dealing with things. But a psychiatrist might well say I am ignoring the other part and that's something I should feel.

Believing that this participant was denying the negative impact of MLLA and the breakup of his family on his well-being, I assumed he was delaying inevitable psychological distress. Speaking with him over the next few months, however, it became clear I was wrong. For this individual, focusing on the logistical demands of building his life in a new home and with new functional limitations seemed to have a protective effect throughout the first few months. As he progressively became more able, he could engage in other coping strategies such as returning to work, spending time with his children, engaging in leisure activities, and planning for the future. There was no evidence of the sudden decline that I had anticipated.

Overall, the trajectory for these patients was one of moderate highs and managed lows. For some, the things that brought the greatest pleasure (SWB) and purpose (PWB) at certain moments in their lives were the same things that knocked them back at other times. For one participant, it was her horses, which she described as both improving and challenging her PWB:

*Interviewer:* Do you still enjoy horse riding?

*Participant:* I do, but sometimes, you know when you just think, if I stopped it, what would I do? Would I just give up everything? Because I could quite easily be like, screw this. Give up. But if I gave them up, I wouldn't have that thing to get back to. It's not even the riding side of things; I've got to look after them twice a day. I've got to go down, muck them out, put them out, bring them in, groom them, and just even that is such a good aim for me. I want to do it; I do like doing them. But sometimes you just, when you're riding, you're like, why do I even bother? But then, when you have a really nice ride, then you think, oh actually, I do know why I do it.

This quote illustrates how valued activities had the potential to support patients' SWB and PWB on certain days but to hinder them on others, hence the oscillating trajectory of *muddling along*.

### **Projection**

The final narrative identified was one of contradiction between the images the patients sought to project and my impressions of them as storytellers. This typology describes a trajectory in which the patients' stories, while reflective of their truth, did not resonate with me as the listener. Here, I shall endeavour to present the patients' stories as they were told to me together with my responses as I recorded them at the time, such that readers may make their own judgements as to the content and purpose of the stories being told.

There were only two participants whose stories seemed to hang upon a narrative of projection. Throughout our interactions, I felt one of these participants was trying to impress. Every story he told seemed designed to emphasise how outstanding he was terms of physical ability and psychological strength, prior to and after MLLA. However, some of the stories were fractured and difficult to follow. This speaks of the chaos narrative described by Frank (2013), in which "life is reduced to a series of present-tense assaults" (p. XV). During each encounter with Todd, I felt as though I was merely a recipient rather than a participant. In Frank's (2010) terms, I was: "the addressee whose presence enables people to tell their stories" (p. 128). Echoing my own experiences, another patient described his experience of the current participant as follows:

He came in. . . . and then he started taking the absolute piss out of me. I mean, I can deal with that. I just turned to him and went, 'Does it feel good?' He goes, 'What?' and I went, 'You know, separating your problems by making fun of everyone else? How do you feel when you go home and there's no one to take the piss out of and you have to think about what you've done and how you are?' I said, 'How you would like it if I

came around and then started talking about your insecurities? You've obviously got them or else you wouldn't be taking the piss out of everyone else.' He was all, kind of, doe-eyed and gave no response whatsoever. He actually said nothing then just turned around and went out of the room and it was just like, this person has such low self-esteem and such little regard for himself that he feels he has to berate and be the best, the projection of being the best amputee in the world.

These words resonate with Hochschild's (1979) concept of emotion work, which refers to the act of trying to change an emotion or feeling in degree or quality. Hochschild notes that emotion work "refers to the effort - the act of trying - and not to the outcome, which may or may not be successful. Failed acts of management still indicate what ideal formulations guide the effort" (p. 561). In this instance, the first participant's apparently failed attempts to manage his self-presentation suggest his ideal of the 'good' amputee involves masking any insecurities with more socially acceptable humour.

This participant's story was framed by the quest narrative described by Frank (2013), illustrated by comments such as: "I've gained my life. I might have lost a limb, but I've gained another future", and, "You can't change what's happened, but what you can change is the future, and just feel at the end of the day, whatever is going to happen, it will only get better". Such attempts at meaning making (i.e., making sense out of an adverse experience by identifying something positive about it; Dunn, 1996) can help individuals who have experienced trauma to retain a sense of cognitive coherence about the world (e.g., Janoff-Bulman, 1992). However, there were moments at which this narrative seemed to be illusory and unsustainable. It seems likely these were the times when a setback forced him to experience his reality as it was, rather than as he wished it to be. These moments left me wondering whether this participant's stories were, at their heart, a strategy for coping with the physical and psychological pain he had experienced since his accident. In holding onto the quest

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narrative, he adhered to a popular Western cultural script, offering a story of growth that people want to hear rather than a less desirable story of suffering. It is possible the telling of such stories also reflected Todd's attempts at reconstructing his own experiences.

The second participant's stories of growth and self-discovery after the loss of his legs also adhered to Frank's (2013) quest narrative. However, where the first participant's narrative was undermined by a lack of meaningful coherence, the second individual's stories about his life after MLLA seemed to reveal all he had lost rather than what he had gained:

I care only about me. That's what I've learned. When you are disabled, when you are an amputee or bilateral, you have to become selfish. So even if you find someone in your life . . . if you open your heart, you open your soul, you are giving them a chance to disappoint you, and that will drag you down, so there is no point for you to do that. A lot of stuff has changed. . . . this is who I am and this is my station, and I have to live with it, because I can't change anything. My legs won't grow again, so I have to move on somehow...and that's how I'm trying to progress, to change...not caring about anything around me. That's the most important thing.

This participant told me that his life had changed "in a good way", however the overall picture I was left with was one of isolation and loss, not only of his legs, but of close relationships, self-acceptance, and autonomy. While moving away from negative relationships, as he describes, could improve his PWB, it did not seem to have supported his SWB. My perception that these stories did not match up with the reality of his experience was reinforced by comments he made, such as, "I learned that from every single person, you have to expect to be disappointed." Where this participant acknowledged the challenges that he had overcome after MLLA (e.g., fear of going out or lack of self-acceptance), he struggled to articulate what had changed, leaving me questioning whether this growth was, in fact, illusory. What he was really describing the change he would *like* to see rather than change he *had* seen? For example:

“When I came here, I was afraid to go outside because I was afraid that I am helpless, basically, so someone could come and nick my phone or my wallet. But after that, everything changed. This fear disappeared.” After this interview, I wrote in my reflexive journal:

I have just been transcribing an interview with [this participant], and, as I typed, I realised that I don’t really believe what he is saying. Or, to be specific, I don’t believe that he is reporting his current experiences. My hunch is that he is telling me about how he wishes he felt, and how he thinks he ought to be, rather than how he actually is. Maybe I am wrong, and he truly has gone through this huge transformation, but something about it just doesn’t connect for me.

Four months after this interview, this participant was attacked in the street. This incident seemed to shatter the fragile world he had created for himself, perhaps as reality punched through the narrative of growth he was trying (consciously or unconsciously) to construct:

That incident took away all my confidence. I am scared to go out. I am 32 years old and I am scared to go outside. I just stay in the house, on the premises. After that I thought, f\*\*k this. I am not going out. I didn’t feel scared before. I have had it with going out and public transport. I tried to take a bus one day when it was raining, and I had to wait for four buses before I could get on, because people wouldn’t move a buggy out of the way. I thought, f\*\*k this.

It is striking that, of the 30 patients who participated in this study, only two told stories so firmly rooted in a quest narrative. These participants were also the only two patients whose stories felt disconnected from reality and were, as a result, difficult to hear. As Frank (2013) noted, “Those living in chaos are least able to tell a story, because they lack any sense of a viable future” (p. XV). It seemed to me that both men were trying to reconcile stories at opposite ends of the narrative spectrum of life post-MLLA: the desire to gain something and the experience of chaos. As a result, their stories lacked coherence and were difficult to

maintain. These are, perhaps, the patients we should be most concerned for: those whose adherence to a culturally desirable growth narrative precludes them from acknowledging a need for help. As Caddick, Smith, and Phoenix (2015) explained, “Narratives act on people in the sense that they constitute certain emotions, beliefs, and practices as appropriate in the context of a particular story, whereas others are necessarily eschewed” (p. 77). While the contradictory quest stories told by these patients, and their enthusiasm for sharing them, suggests that it may be relatively simple for healthcare practitioners to identify those who are struggling to come to terms with their new reality, there remains the question of what next? How might we open up alternative stories and provide narrative resources that free patients from the constraints of dominant and popular narratives, and instead offer them the means to find their new normality?

### **Implications for Rehabilitation Practice**

These narrative typologies provide a novel method of understanding the experience of MLLA, and the hospital-to-home transition in particular, by offering new insight into how the stories patients tell, and the narratives they embody, may affect their recovery. These findings may provide an important point of reference for healthcare providers, enabling them to identify patients who might be particularly susceptible to a post-discharge decline in SWB and PWB. It also offers insight into how narratives may be harnessed to effect positive change for those patients struggling to adapt to their new circumstances after MLLA. This section will explore some of the questions and implications for MLLA rehabilitation practice that were raised in the preceding section.

The narrative trajectories presented raise two issues relating to the meeting or managing of patients’ needs and expectations in rehabilitation programmes. First, patients who seem to be very positive initially may be the ones who need help later on. Second, those who would derive the greatest benefit from assistance may be those least likely to acknowledge there is a problem. These issues raise two additional questions: (1) how do we identify patients who may



be likely to struggle once they return home, and (2) how can rehabilitation practitioners assist those who do not acknowledge (whether to themselves or others) the need for support? The findings offer a possible solution to the first question. Specifically, patients who were experiencing the greatest difficulties post-MLLA were those who adhered closest to narratives of *accelerated decline*, *illusory cure*, and *projection*. These were the patients who told stories either of high expectations and ambitions, great positivity and enthusiasm (*illusory cure* and *projection*), or of low motivation and autonomy, and no expectation of improvement (*accelerated decline*). Those patients whose stories revealed more measured expectations (*adaptation*, *muddling along*), however, were better able to sustain a gradual and progressive increase in SWB and PWB even after returning home. Therefore, attending to the stories that patients tell during rehabilitation may offer healthcare practitioners a degree of insight into their likely trajectory upon leaving.

The question of how to support patients who are no longer attending the hospital regularly, and who may not request or agree to interventions such as counselling, may also be tentatively answered. If healthcare practitioners are able to identify patients who seem to be adhering to high-risk narratives (*accelerated decline*, *illusory cure*, and *projection*) during the early stages of rehabilitation or, even, during primary care, interventions could be delivered that open up alternative and more facilitative (if less inspirational) narratives (e.g., *adaptation* or *muddling along*) and encourage adaptive self-regulation. Creating opportunities for the sharing of diverse recovery stories, for example, may enable patients to see alternative trajectories and possibilities. Griffin and Phoenix (2016) suggested that one way in which individuals may learn to tell a new story (or self-renew) is through telling counter-stories that offer resistance to dominant cultural narratives. The authors suggested that, when told collectively, “these ‘new’ stories present the possibility for both individual behavioral and social change” (p.14) and prompt us to re-evaluate ourselves and our potential. In the context

of this study, a counter-story might be one of *muddling along* as opposed to a story of cure or restitution. The sharing of stories, in itself, may offer patients a means of alleviating their own struggle. The impact of narratives for one who is suffering was summed up most poignantly by Frank (2013) as follows: “Suffering does not magically disappear when the tale is told, but the more stories I heard the less space my own suffering seemed to take up. I felt less alone” (p. xi). If a patient’s narrative resources can be expanded in this way, this may present them with more options and coping strategies (e.g., assimilation and accommodation) to deploy as and when necessary upon returning home.

The process of analyzing patients’ stories and identifying these narrative typologies made it apparent that patients whose attendance overlapped tended to embody similar narratives of recovery. We propose no conclusions as to why this might be, researchers have indicated that patients derive much of their knowledge and understanding of life with MLLA from their peers (e.g., Grech & Debono, 2014) and the narrative environment. We also know that narratives can be an effective means of communicating information about physical injury (e.g., Smith et al., 2015). Therefore, it seems plausible that more experienced patients may shape the narrative resources made available to newcomers by sharing their rehabilitation stories. To quote Frank (2013): “people’s ability to have experiences depends on shared cultural resources that provide words, meanings, and the boundaries that segment the flow of time into episodes. Experiences are very much our own, but we don’t make up these experiences by ourselves” (p.13). The current findings suggest that, while individuals told their own stories of rehabilitation, these were mapped onto narratives already circulating in the centre.

What, then, caused these cultural narratives to shift at certain points across the 16-month data collection? Possibly, patients entering the centre brought with them new and different narrative resources that were then made available to others. Perhaps, the rotation of

physiotherapists caused a similar effect. Alternatively, the shifting relationships between patients attending the centre at any one time, some of whom formed close-knit cliques and some of whom argued, may have affected the content and extent of information sharing between patients. Irrespective of the cause of such shifts, it is important for healthcare practitioners to note the likelihood of patients sharing stories and, thus, narrative resources, and to be mindful of the effect that may have on each individual's recovery trajectory.

In closing, it is also important to note that the narrative typologies here represent a moment in time for these participants. Extant research indicates that psychosocial responses to MLLA continue to fluctuate many years after the event itself (for a review, see Horgan & MacLachlan, 2004). In light of this, and the dynamic nature of patients' recovery trajectories as described here, it would be beneficial to conduct similar research that extends over a period of several years. It is possible, for example, that patients embodying the narrative of the *illusory cure* at 12 months post-surgery may have shifted to *adaptation* at 24 months. If this were to be the case, it would be useful to understand why, when, and how such shifts occur, and the impact this has upon the individual's well-being. Further research is also needed that considers the possible influence of demographic factors such as age, race, gender, and class, and the impact these may have upon the narrative resources that are made available for individuals with MLLA. Studies focused on the interaction between age and wellbeing trajectories over time may be of particular interest, given the way our findings have challenged traditional assumptions about age-related responses to MLLA. The participant age range in this study was extensive, yet there were no clear trends with respect to age and embodiment of a certain narrative. This echoes work by other researchers who are dispelling stereotypes of the ageing process (e.g., Phoenix & Sparkes, 2009; Phoenix, Smith, & Sparkes, 2010), and suggests this to be an area worthy of further exploration.

### Conclusion

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In this article, we present the narrative typologies mapped by patients' stories of recovery during the first year after MLLA: *accelerated decline*, *adaptation*, *illusory cure*, *muddling along*, and *projection*. These narrative typologies contribute to cumulative advances in the field by building on extant research, as well as providing novel research outcomes through the development of narrative typologies based on rigorous data collection over a 16-month time period. These findings may provide an important point of reference for healthcare providers, enabling them to identify patients who might be particularly susceptible to a post-discharge decline in SWB and PWB, not through generalization on the basis of factors such as gender or age, but on the basis of the individual stories they tell. It also offers insight into how narratives may be harnessed to effect positive change for those patients struggling to adapt to their new circumstances after MLLA.

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